

Members:

Rep. Vanessa Summers, Chair  
Rep. Markt Lytle  
Rep. Robert Alderman  
Rep. Cleo Duncan  
Sen. Richard Worman  
Sen. Kent Adams  
Sen. Allie Craycraft  
Sen. Joseph O'Day

Lay Members:

Hugh Beebe  
Capt. Michael Carmin  
Nan Daley  
Donna Ott  
Herbert Grulke  
Becky Zaseck

LSA Staff:

Susan Preble, Fiscal Analyst for the Commission  
Ann Naughton, Attorney for the Commission

Authority: IC 12-11-7



## COMMISSION ON AUTISM

Legislative Services Agency  
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Indianapolis, Indiana 46204-2789  
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### MEETING MINUTES

Meeting Date: September 21, 1998  
Meeting Time: 1:00 P.M.  
Meeting Place: State House, 200 W. Washington St.,  
Room 233  
Meeting City: Indianapolis, Indiana  
Meeting Number: 5

Members Present: Rep. Vanessa Summers, Chair; Rep. Robert Alderman; Rep. Cleo Duncan; Sen. Richard Worman; Sen. Kent Adams; Sen. Allie Craycraft; Hugh Beebe; Capt. Michael Carmin; Nan Daley; Donna Ott; Herbert Grulke; Becky Zaseck.

Members Absent: Rep. Markt Lytle; Sen. Joseph O'Day.

### CALL TO ORDER

Rep. Summers called the meeting to order at 1:20 p.m.

### FSSA PRESENTATION ON WAIVER PROCESS AND BARRIERS

**Debra Wilson, Director, Division of Disability, Aging & Rehabilitative Services (DDARS), Family and Social Services Administration (FSSA)**, testified that her Division has conducted internal meetings with staff from the Division of Family and Children (DFC) and Area Agencies on Aging (AAA) to examine the steps and processes involved in the determination of eligibility for the autism waiver, and that process recommendations will be made in October. Ms. Wilson reported that her Division is currently involved in training efforts with DFC supervisors in order to facilitate a better understanding of the Medicaid waiver process. She then introduced John Hill as the new Deputy Director of DDARS.

Rep. Summers asked why there are empty waiver slots when there are over 400 people on the waiting list. Mr. Hill stated that he did not know the exact number of missing slots, but that the DFC eligibility process seems to be the obstacle. He explained that the final determination of Medicaid eligibility is done by the DFC. Mr. Grulke stated that the AAAs also have responsibility for processing the initial applications for the waiver.

Ms. Zaseck proposed that the administration consider having just one agency determine eligibility rather than several. Rep. Summers agreed and stressed the importance of streamlining the process for families. Ms. Daley asked who manages the waiver waiting lists. Ms. Wilson stated that DDARS manages the waiting lists and often helps families obtain other services to help in crisis situations that can occur while they wait for an autism waiver slot.

Ms. Daley expressed concern that when a slot becomes available, it can't be filled immediately because the necessary paperwork has not been completed. She asked whether eligibility could be determined before a slot becomes available. Ms. Wilson explained that it's important to determine eligibility before a slot is filled, rather than filling a slot and determining eligibility later.

Rep. Alderman asked about the moratorium on group homes. He told the Commission about a specific family's difficulty finding a space in a group home for their daughter. Ms. Wilson said she would investigate the family's situation.

Rep. Summers stated her belief that some individuals require a group-home setting. She expressed frustration about the moratorium because she has been told there are 500 beds available statewide.

## **CURRENT STATUS OF GROUP HOMES**

**Sue Lindborg, Christole, Inc.**, distributed an informal survey of 19 service providers to determine the availability of residential services for children with developmental disabilities.<sup>1</sup> Ms. Lindborg testified that the Association of Retarded Citizens (ARC) of Indiana estimates that 5,000 people are waiting for services in Indiana, it is not known how many are children. She explained that residential services cost more than group homes. Ms. Lindborg stated that a major problem with group homes is the lack of a uniform certification process, which results in many group homes operating without standards and with little quality of care. She said that she receives many calls from families looking for group home placements for their children. Ms. Lindborg distributed copies of her remarks and ended her testimony by stating that she advocates four and five-bed group home settings.<sup>2</sup>

Mr. Grulke commented that he received three calls in the last week from parents who are unable to place their children in group homes in Indiana because of the moratorium. He explained that some families are incapable of caring for their children in their own homes, necessitating a need for the group-home option. Ms. Wilson responded by saying that DDARS needs to determine the demand for beds in group homes before lifting the moratorium. She explained that many children are "aging out" of DFC care and group homes. Ms. Wilson recognized the lack of beds for children, and stated the answer is to identify who they are and whether they are interested in "cascading" from residential to community care.

Ms. Daley expressed concern about the elimination of choices for families and said that group homes serve an important purpose in a variety of situations. She stated that power should not be taken away from families because they are in the best position to know what is best for their children. Ms. Daley said that the saddest situation is for a family to decide to send their children to a group home. Kathy Gifford, Assistant Secretary, FSSA, agreed with the need to provide families with choices and a continuum of care. Rep. Summers expressed concern that the 317

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<sup>1</sup>A copy of the survey is on file at the Legislative Information Center, Room 230, State House, Indianapolis, Indiana. The telephone number of the Legislative Information Center is (317) 232-9856, and the mailing address is 200 West Washington St., Suite 301, Indianapolis, Indiana 46204-2789.

<sup>2</sup>A copy of Ms. Lindborg's remarks is on file at the Legislative Information Center. (See footnote 1).

Task Force does not recognize the need for group homes, and reiterated that not everyone can live in the community successfully.

Ms. Wilson responded that the Task Force's mission is not to close all group homes, but to recognize that persons with developmental disabilities are individuals and have a right to make choices from available options and services. She stressed that the idea behind the 317 Task Force is choice, and to eliminate group homes would not be consistent with that idea. Rep. Summers stated her concern that group homes will lose funding. Ms. Lindborg commented that children age out of residential care and need a place to go when they become adults.

**Penny Githens, parent of a child with autism and member of the South Central Indiana Chapter of the Autism Society of America**, read a letter from the Mufson family of Bloomington who could not attend the meeting.<sup>3</sup> The Mufsons requested that the Commission develop and support legislation to fund services that provide a range of community-based options for people with developmental disabilities, end the moratorium on group homes, eliminate the waiting lists and treat people with disabilities as individuals. Ms. Githens also distributed copies of a letter she wrote to the Commission regarding insurance coverage for persons with autism.<sup>4</sup>

### **ADMINISTRATIVE COSTS BILLED BY SERVICE PROVIDERS**

**Costa Miller, Indiana Association of Rehabilitative Facilities (IN-ARF)**, testified as a representative of a wide variety of providers since 1974. Mr. Miller stated he could not advocate for more group homes at this time. Mr. Miller testified that 400 new group homes were built in the last biennium budget of Governor Mutz's tenure, but then the Budget Agency asked for a moratorium on group homes to convert funds into waiver slots. He stated that in 1991, the Budget Agency asked for another moratorium in order to put more funds into waiver services.

Mr. Miller stated that only if documented evidence indicates a need for additional group homes should more be added. He testified that the state does not need to build more of anything right now because it is too early in the 317 Task Force plan to determine our needs.

Rep. Alderman then asked Mr. Miller why overhead costs are so great for service providers. Mr. Miller responded by explaining that current caps on administrative costs are set by the Social Security Block Grant program (SSBG) at a maximum of 16-18%. Mr. Miller stated that respite care is a bad example because more money is spent on costs associated with overhead than on the actual care provided.

**Tracy Mitchell, CPA, Bradley & Associates**, began his testimony by crediting the state for the work being done to improve the service delivery process. He testified that parents often ask how a provider can bill \$16 an hour for respite care services, yet only pay the worker actually providing the care \$6 an hour. Mr. Mitchell distributed a handout which outlined typical costs for non-profit providers.<sup>5</sup> He explained that because waiver rates have not been adjusted for many years inflation is working against providers. Mr. Mitchell reported that turnover is high because employees receive a low hourly wage. He suggested that the lack of funds is reflective of the value society puts on caring for the developmentally disabled. He explained that the tradeoff is

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<sup>3</sup> A copy of the Mufson's letter is on file at the Legislative Information Center. (See footnote 1).

<sup>4</sup> A copy of Ms. Githens' letter is on file at the Legislative Information Center. (See footnote 1).

<sup>5</sup> A copy of Mr. Miller's handout is on file at the Legislative Information Center. (See footnote 1).

that if providers pay their employees a higher hourly wage, they cannot provide as many hours of service to as many families.

Mr. Grulke reported that as a service provider, he has lost 25% of his labor force to the casinos in the area which pay a higher hourly wage. He stated that part of turnover is a function of the labor market and cannot be avoided.

Kathy Pratt, Director of the Indiana Resource Center for Autism, testified that many families have difficulty receiving consistent, quality services, and that the families often train the workers, not the service provider. Ms. Pratt stated that more funds should go to families through a voucher system since they are often doing all of the administrative work anyway.

Ms. Daley theorized that if hourly rates increased, turnover would decrease and supervision and other administrative costs that providers incur would also decrease. Mr. Mitchell agreed but explained that some administrative costs remain fixed. He also stated that there is no point in increasing rates without the implementation of quality assurance measures, like a toll-free number that families could use to lodge complaints and report problems.

## **OTHER COMMISSION BUSINESS**

Rep. Duncan reported that Ms. Pratt will be the keynote speaker at the National Autism Conference this year. Ms. Pratt then distributed copies of the Center's Final Report for the period of July 1, 1997 through June 30, 1998.<sup>6</sup>

Ann Naughton, the Commission's staff attorney, distributed copies of two preliminary drafts, PD 3325 and PD 3321.<sup>7</sup> Both P.D.s add autism to the list of eligible conditions under the Children's Special Health Care Service program. Rep. Summers stated she prefers PD 3325 because it is simpler. Rep. Alderman moved to recommend PD 3325, Sen. Worman seconded the motion, and the motion passed by consent.

Sen. Worman said that he would like the Commission to recommend a resolution proposing that the State of Indiana cover autism and include the funding to do so in the budget. He estimated that a premium cost to the state for \$10,000 annual benefit would cost \$6 a month per employee.

Rep. Alderman stated that he would like to eliminate the requirement that funds not used by FSSA be reverted to the general fund.

## **ADJOURNMENT**

Rep. Summers declined to set the next meeting date, but stated that a notice would be sent out when the date is chosen. With there being no further business before the Commission, Rep. Summers adjourned the meeting.

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<sup>6</sup>A copy of the Center's Final Report is on file at the Legislative Information Center. (See footnote 1).

<sup>7</sup>Copies of PD 3325 and PD 3321 are on file at the Legislative Information Center. (See footnote 1).